Excellence for All: A Community Viable Coaching Initiative throughout Georgia

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Excellence for All: A Community Viable Coaching Initiative Throughout Georgia

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EMORY UNIVERSITY SCHOOL OF MEDICINE

Marcus AUTISM CENTER
NIH Autism Center of Excellence

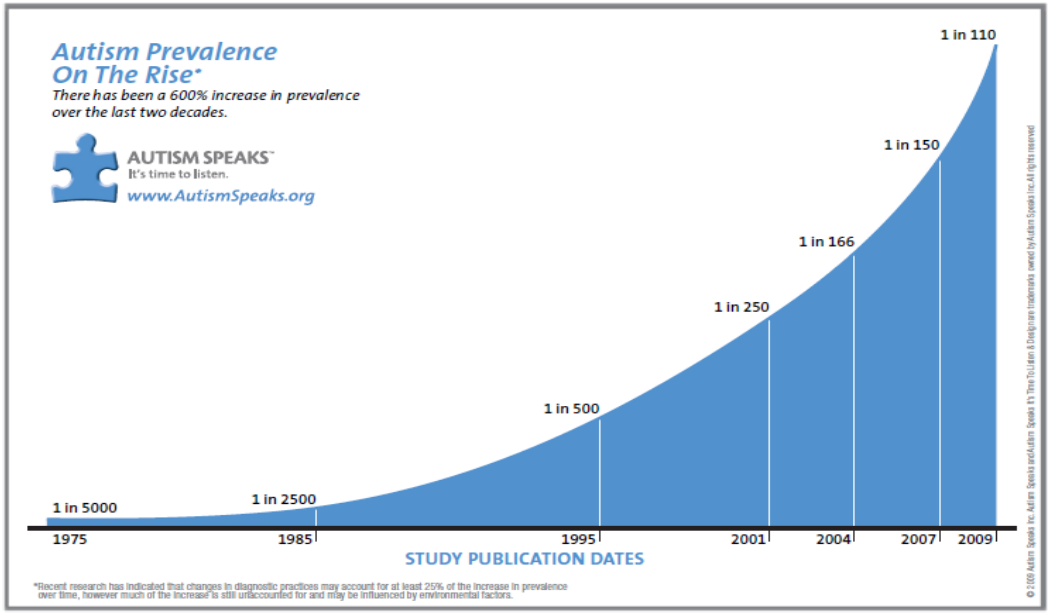
Children's Healthcare of Atlanta

Objectives

- Participants will be able to identify early red flags for autism.
- Participants will learn evidence-based components of adult learning.
- Participants will learn evidence-based components of collaborative coaching.
- Participants will be given an account of community viable collaborative coaching in the natural environments of young children.

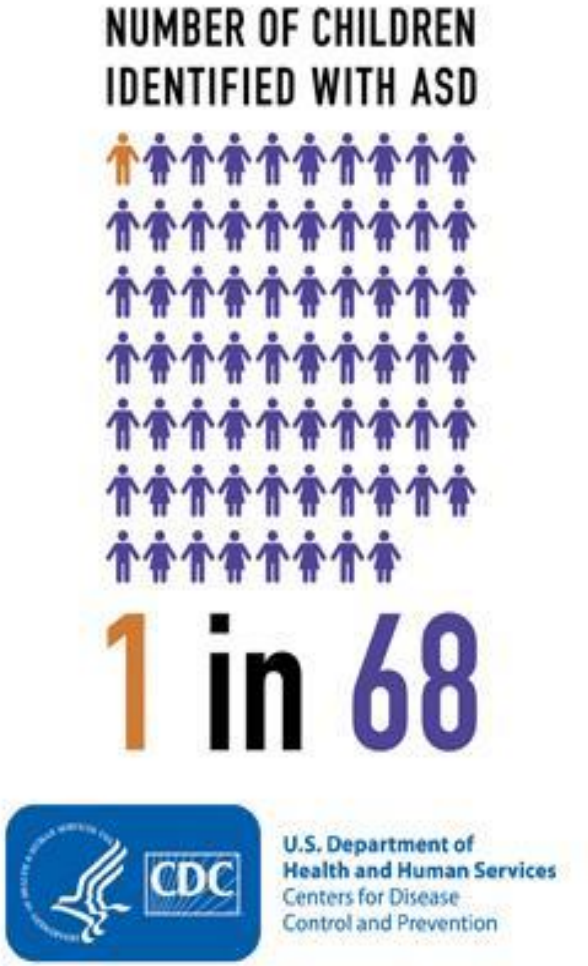
Autism in America

For every 68 children born in the US, one of them has Autism



1 in 42 boys, 1 in 189 girls

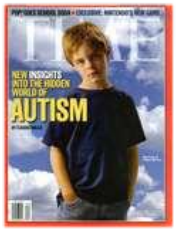
Autism Compared to Other Common Pediatric Diseases/Conditions



Disease/Condition	Prevalence Rate
Autism Spectrum Disorders	1:68
Congenital Heart Defects	1:125
Childhood Cancer (all types)	1:330
Juvenile Diabetes	1:500
Cystic Fibrosis	1:5,000
Muscular Dystrophy	1:20,000

Autism and Other Developmental Delays are a Public Health Challenge

- Autism Prevalence: 1 : 68 [1:42 in boys]; 1:10 developmental delays
- Community Disparities (dx; access)
- Societal Cost/Year in the US: $ 136 billion
- Lifetime Cost of Care Per Child: $ 2.4 million
- American Academy of Pediatrics recommends screening for autism at 18 and 24 months
- Despite strong genetic bases, diagnosis is behavioral, reference standards excellent (ADI-R/ADOS/expert clinician)
- Majority of autism diagnoses in US outside academic medical centers
  - Usage of ADI-R and ADOS in fewer than 0.1% and 2.1%, respectively
  - Questionnaires/checklists in 30%
- Importance of early diagnosis and intervention for lifelong outcome and cost of care
- <20% of children identified before age 3 years



Challenges and Opportunities:
Reducing Age of Diagnosis and Access to Care

- Brain disorder of genetic origins
  - The risk of an ASD for subsequent siblings of children with ASD is 20%**; 20%; 10%
  - BUT Adverse outcomes can be attenuated
- Importance of early diagnosis and intervention for lifelong outcome and cost of care
  - -Yet we are dependent on the currently available methods of screening, detection, diagnosis, and intervention.
- American Academy of Pediatrics
  - Screening (18 and 24 months), but still low uptake
  - 8% of primary care providers routinely screen for ASD
  - Studies have shown that 1/3 to 1/2 of parents of children with ASDs notice a developmental problem before their child's first birthday.
  - 80% of parents express concerns by 24 months of age.
- Median age of diagnosis in <u>US: 4-6 to 5.7 years</u>
  - Later still in disadvantaged communities
- No Community-viable system of care
  - Reimbursement systems NOT in place

Normative Social Development

- Infants come into the world "pre-wired" for social engagement.
  - From the first days of life infants are profoundly sociable
  - Human faces/voices are the most interesting stimuli on the environment
- Early emergence of:
- Selective attention
- Social engagement
- Social reciprocity
- Attachments
- Social Communication Skills
- Relationships

The Neurology of Social Competence

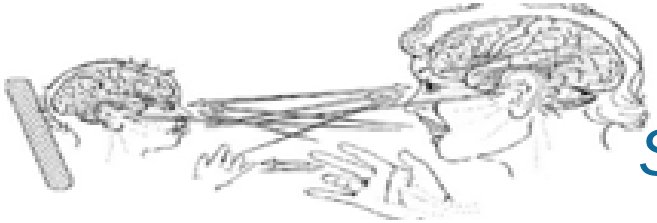
- When neurotypical infants look at peoples' faces, regions in the limbic system "light up" with endorphins and reward that child.
- By 6 months of age, a child begins to follow gaze and can recognize when they have lost the caregiver's attention.
- By 10 months of age, a child begins to shift gaze from a caregiver to objects of reference to predict and anticipate the actions of others.
- By 12 months of age, a child will initiate shared attention on desired items or items that are of interest to the child.
- These capacities foster expertise about the social world.

The Neurology of Social Competence

- These capacities ensure that a neurotypical child:
  - is drawn toward social vs. non-social stimuli
  - derives pleasure from this engagement
  - notices attention shifts of others
  - initiates bids for engagement, actions, and objects of interest
  - develops language about people and intentions to share these messages
  - engages in interactions using expected social behaviors (e.g., adhering to social norms) in order to maintain relationships over time

Autism Disrupts the Platform for Brain Development

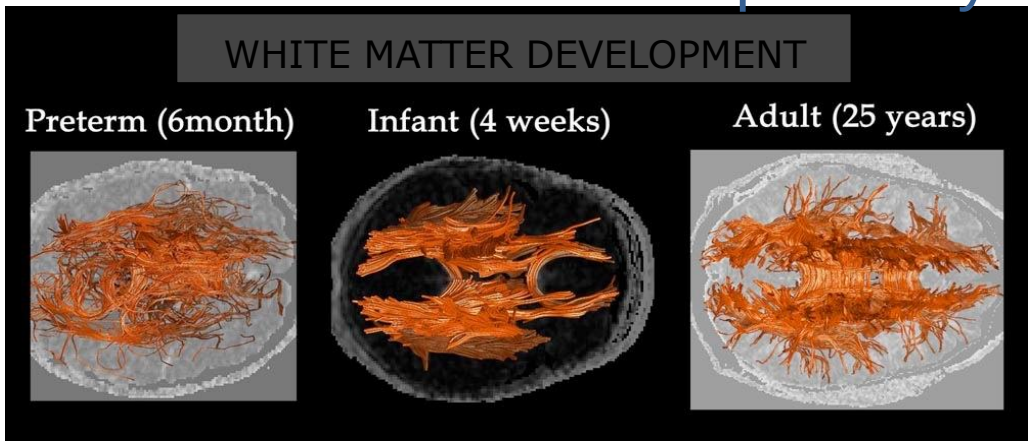
Born to Socially Orient



MH Johnson PhD

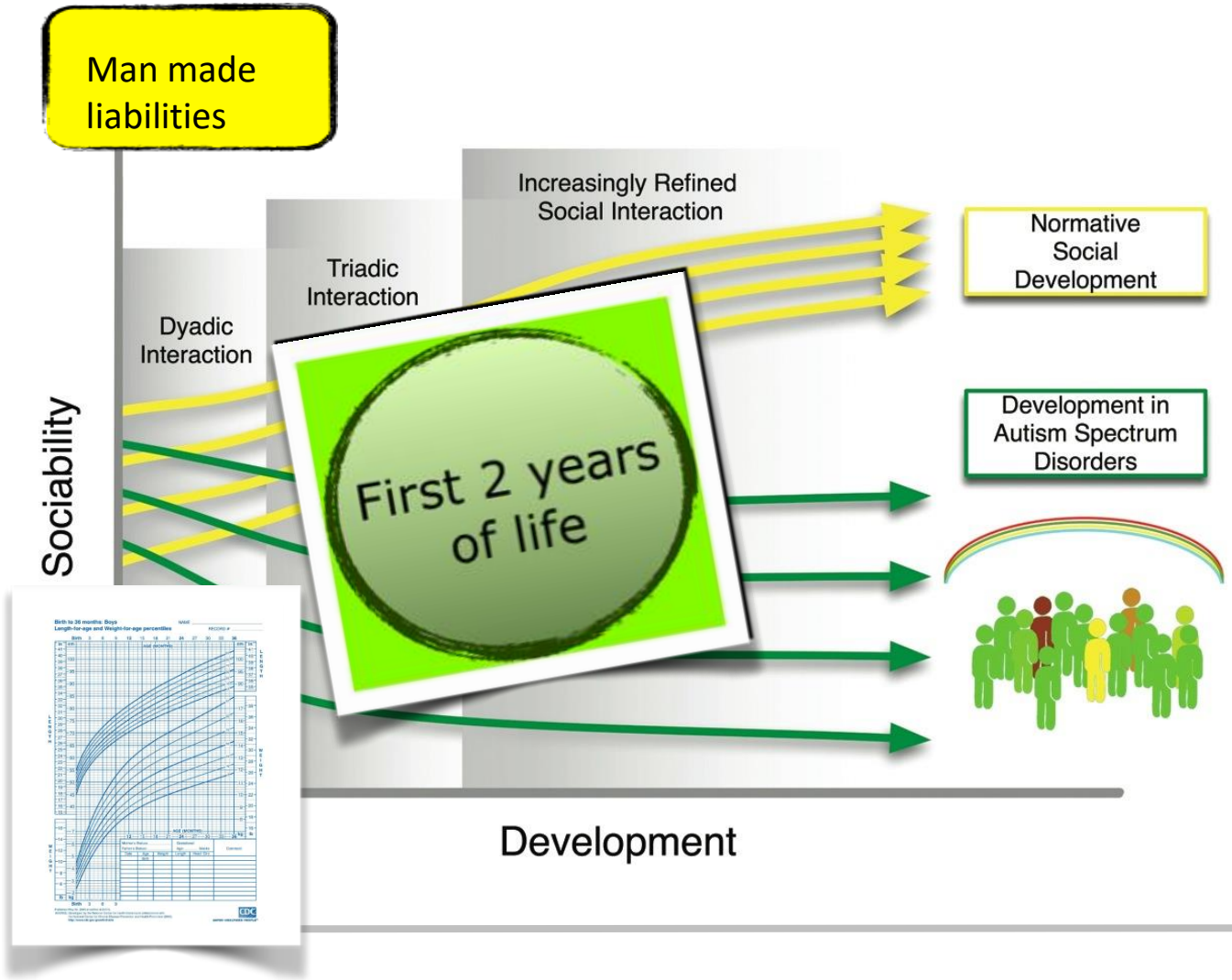
Reciprocal Social Interaction

Neuroplasticity



H-J Park PhD

GENETIC MECHANISMS OF SOCIALIZATION
BEHAVIORAL LIABILITY
SYMPTOMS



No Genetic Determinism

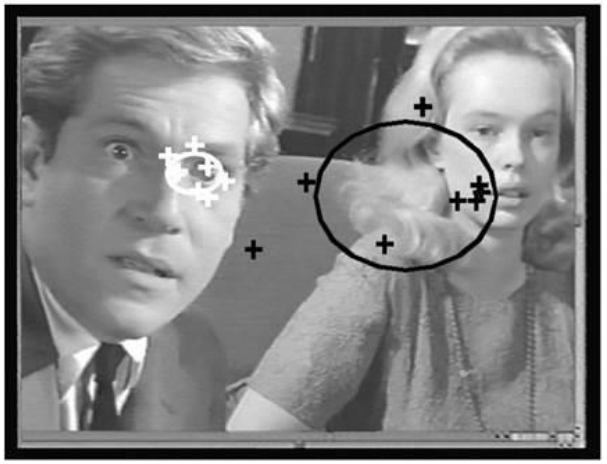
No Environmental Determinism

No Brain Determinism

Jones et al. (2008). *Arch Gen Psy*, 65(8), 946-54; Klin et al. (2009). *Nature*, 459, 257-61; Jones & Klin (2009). *J Am Acad of Child Psy, 48(5): 471-3; Jones & Klin (2013). Nature*, 504, 427-431*; Klin et al. (2014). Neurosci Biobehav Rev.*

Unique Neurological Differences in ASD

- Children with ASD:
  - Show limited neural sensitivity to social stimuli and tend not to look toward people's faces.
  - Tend to look at the mouths of the speaker.
  - Miss gaze shifts between people and objects.
  - Have difficulty predicting actions and initiating bids for engagement.



Unique Neurological Differences in ASD

- Similarly, when neurotypical children hear speech sounds, these are processed as social or intentional stimuli. Children with ASD simply hear sounds, making the intentions of individual words more ambiguous.

- Individuals with ASD tend to process social stimuli (e.g. faces, speech sounds) in regions of the brain typically reserved to process images and sounds that are non-biological.

- This makes predictions of actions, intentions, and emotions less efficient and more intellectual.

Infants At-Risk for ASD

- Lack of, or attenuated joint attention skills
- Less interest in interactive games
- Less imitation
- Infrequency in looking at objects held by others
- Aversion to touch
- Decreased flexibility in play
- Decreased variety of toy choices and play themes
- Less appropriate play with objects
- Atypical patterns of social orienting
- Lower frequency of looking at others
- Contentedness when alone
- Poor response to name
- Reduced verbalizations/cooing
- Reduced use of gestures
- Disrupted affect regulation
- Reduced affective expressions
- Less affection toward familiar people and/or Increased negative affect

Toddlers At-Risk for ASD

- Abnormalities in social relatedness…
  - abnormal eye contact
  - limited social smile
  - limited interest in other children
  - poor response to name

- Limited competence with social communication…
  - difficulty understanding communicative gestures from others
  - difficulty using gestures
  - decreased desire to share interests through pointing, giving and showing
  - the child may use others as a “tool”
  - A low frequency of verbal or nonverbal communication
  - Atypical affect regulation such as limited sharing of affect or a range of facial expression
  - Unusual vocalizations, body movements and sensory behaviors
  - Limited functional play, an absence of pretend play and repetitive interests/play

Effects of Core Deficits

Diagnosis after age 3 means that children are missing the critical window of opportunity to receive intervention that can stop the cascading effects that core social communication deficits can have on developmental outcomes.

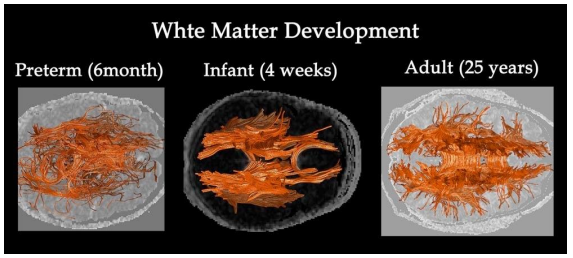
Two Major Priorities in the Field

- **Reducing the age of diagnosis**

Early diagnosis means early treatment

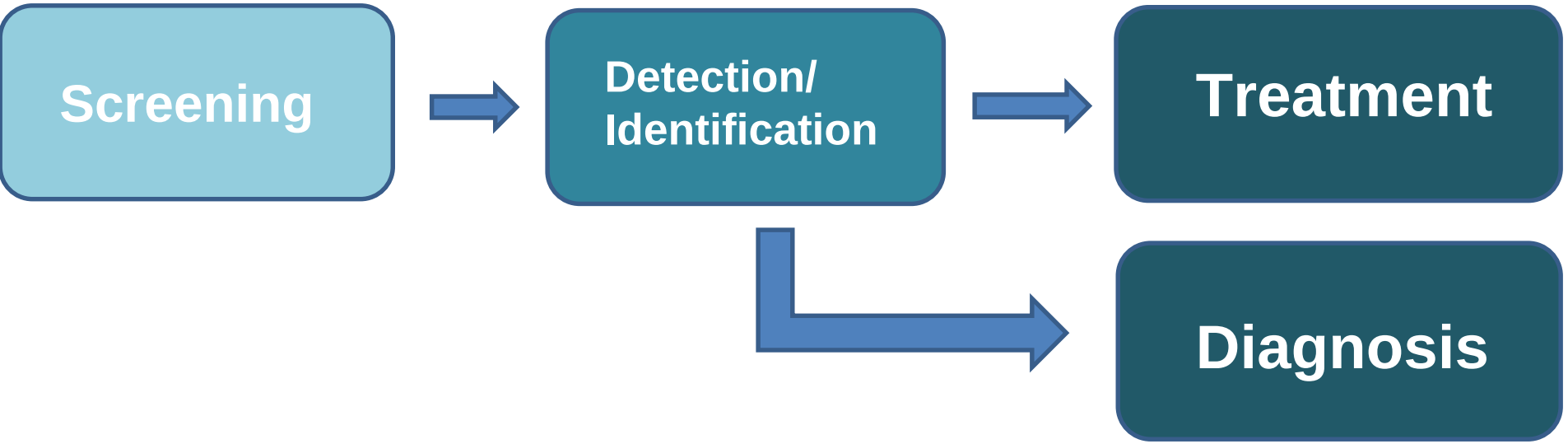
- **Improving access to early treatment**

Early treatments means impacting brain growth during critical windows of development

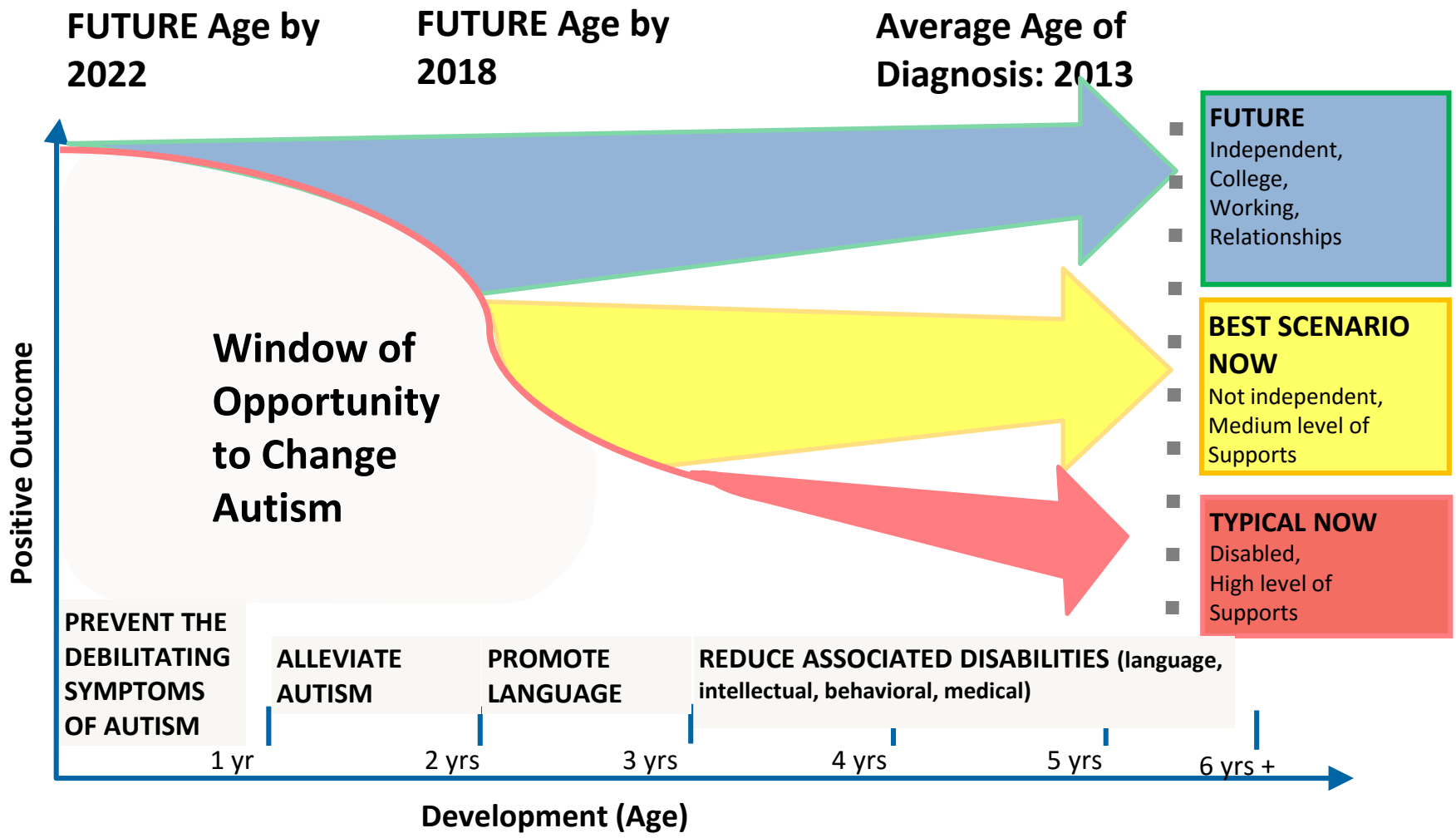


Hae-Jeong Park, PhD

- *Access to diagnosis should not prohibit intervention for red flags.*



Vision…Change the Nature of Autism for Children of Tomorrow



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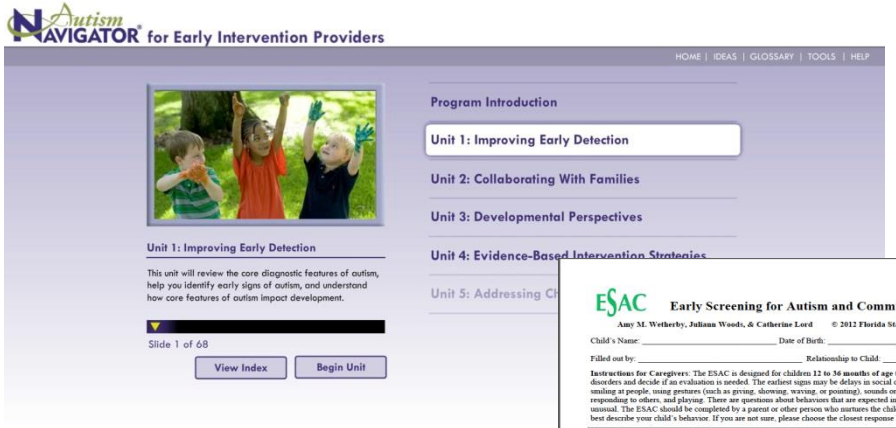
Barriers to Early Screening and Detection

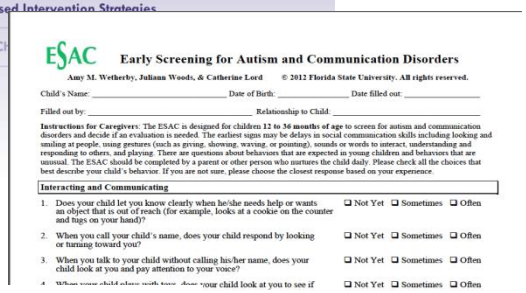
- Subtle symptom-expression early on
- Diagnostic differentiation early on
- Stability of diagnosis
- Uptake of ASD screening into general pediatric practice remains limited
  - Time restrictions
  - Reimbursement issues
  - Use of available methods
- Dependence on clinician knowledge of ASD
- Recognition of early warning signs
- Willingness to act on clinical judgment

Emerging Methods to Facilitate Early Screening, Detection, and Intervention

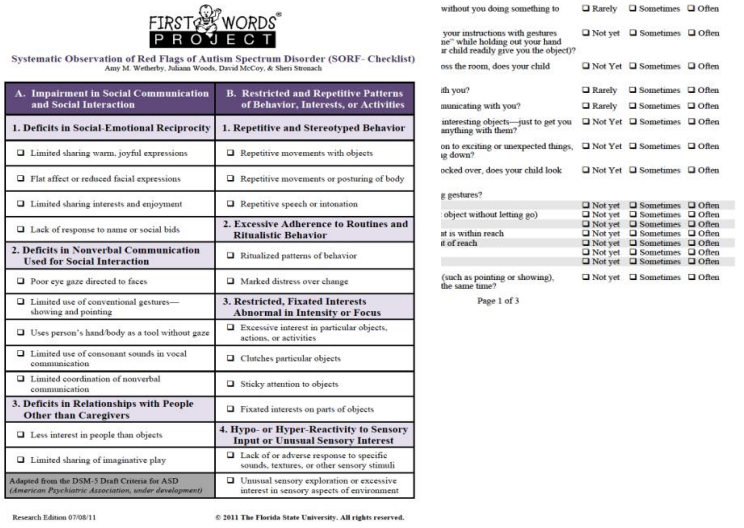
- Autism Navigator



- ESAC/Smart ESAC

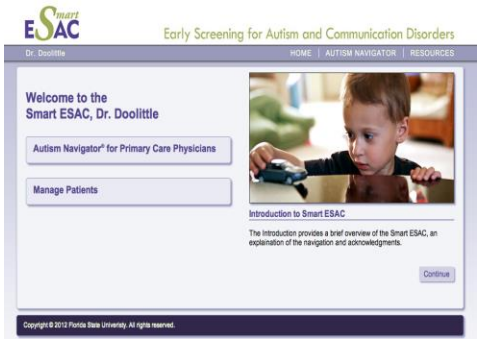


- Clinical Skill/Judgment-SORF



Early Screening- The Smart ESAC

- CSPs will be provided with mobile devices that families will use to complete the Smart ESAC (Early Screener for Autism and Communication Disorders)
- ESAC contains 10 broadband questions
- Depending on parent response, these questions may be followed by 20 additional questions to screen for autism
- Children with a positive screen will be referred to early intervention for further evaluation



Barriers to Diagnosis for ASD

Barriers to Early Intervention

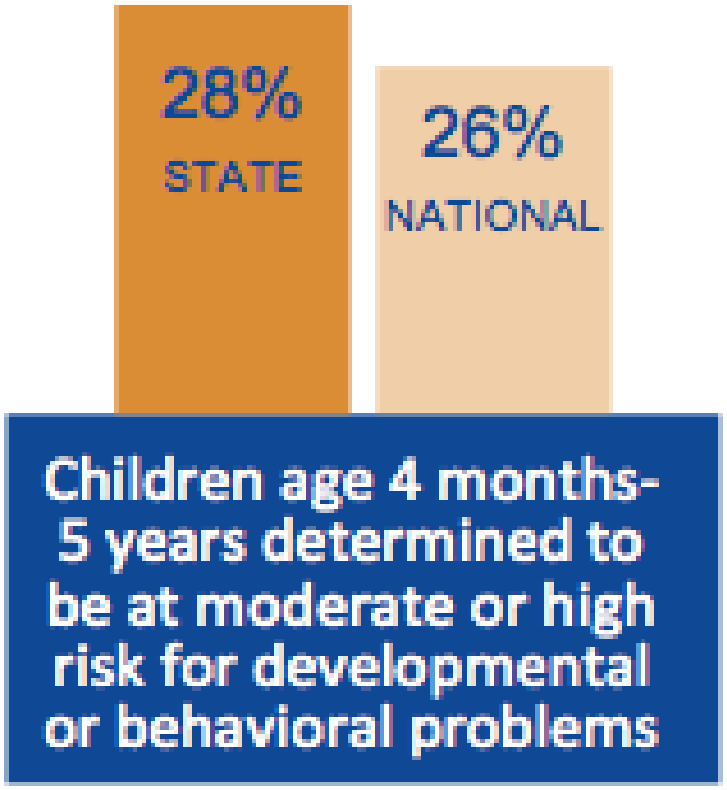
- Intervention has the greatest impact on autism if **it begins before 3 years of age.**

<u>80% of children who need early intervention are missed.</u>

(CDC, 2009; Filipek, Accardo, Baranek et al., 1999; NRC, 2001; USDOE, 2011)

Barriers to Early Intervention

Only 2% of Infants and Toddlers in Georgia receive Part C Early Intervention Services



Barriers (and Opportunities) to Early Screening and Detection

- 61% of children under the age of five are in regular childcare, with the remaining percentage of children primarily being care for at home by parents or caregivers.
- Therefore, **parents and childcare providers** are the most community viable agents of change at the front line of both detecting and providing appropriate supports and services for young children at risk for ASD.

(U.S. Department of Health and Human Services, U.S. Department of Education, 2014)

National Research Council (2001)

Children with ASD should receive **25 hours per week** of active engagement in systematically planned, developmentally appropriate educational activities.

Evolution of Intervention for ASD

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Historical Perspective

- Prior to the 60s, many believed that children with ASD could not learn.
- 1960s and 1970s: Use of operant conditioning became increasingly popular.
- Lovaas (1987) clinical trials caused paradigm shift.

Limitations of Behavioral Intervention

- DTT limitations
- Cost of ABA is $30,000-$60,000/year per child
- Shortage of trained ABA professionals
- Behavioral research largely focused on language and cognition as primary outcomes
- DSM-5 emphasis on **social impairment**
  - Needed focus on social reciprocity in intervention

(Solomon et al., 2014; Koegel et al., 1998; Schreibman et al., 2015)

Naturalistic Developmental Behavioral Interventions (NDBIs)

- Implemented in natural settings
- Involve shared control between child and therapist/caregiver
- Utilize natural contingencies
- Utilize a variety of behavioral strategies to teach developmentally appropriate and prerequisite skills

(Schriebman et al., 2015)

Everyday Activities

Caregiver-Mediated Interventions

- Several controlled, single-subject and quasi-experimental studies and more recent randomized clinical trials suggest that including a caregiver-coaching component accelerates developmental progress in ASD
- Typically less costly and more easily implemented
- Focused on social reciprocity
- NRC (2001) recommends that intervention include a family component

(Wong et. al, 2013; Lord, Luyster, Guthrie & Pickles, 2012; Anderson, Oti, Lord & Welch, 2009)

Caregiver-Mediated NDBIs

- ESDM (Early Start Denver Model)
- Project ImPACT (Improving Parents as Communication Teachers)
- EMT (Enhanced Milieu Teaching)
- PRT (Pivotal Response Training)
- JASPER (Joint Attention Symbolic Play Engagement Regulation)
- ESI (Early Social Interaction Project)

(Schreibman et al., 2015)

NDBI "Secret Sauce"

- Following the child's lead and interests
- Environmental arrangement
- Natural reinforcement
- Use of prompts and prompt fading
- Balanced turns within object or social play routines
- Modeling
- Contingent imitation
- Broadening attentional focus of the child

(Schreibman et al., 2015)

NDBI "Secret Sauce"

- Three part contingency
- Manualized practice
- Fidelity of implementation criteria
- Individualized treatment goals
- Ongoing measurement of progress

(Schreibman et al., 2015)

The Bridge…

- Taking highly effective interventions and creating a community viable, equal opportunity for all.
- Community viable means:
  - Cost efficient
  - Scalable
  - Maintainable
  - Accessible
  - Universal
- Community viability translates to taking the empirically validated methods and allowing them to be delivered in any community to individuals of any educational and any financial background.
- Providing evidence-based parent-implemented intervention that is commiserate with current Primary Service Provider model.

How do we continue bridging the gap between science and community practice?

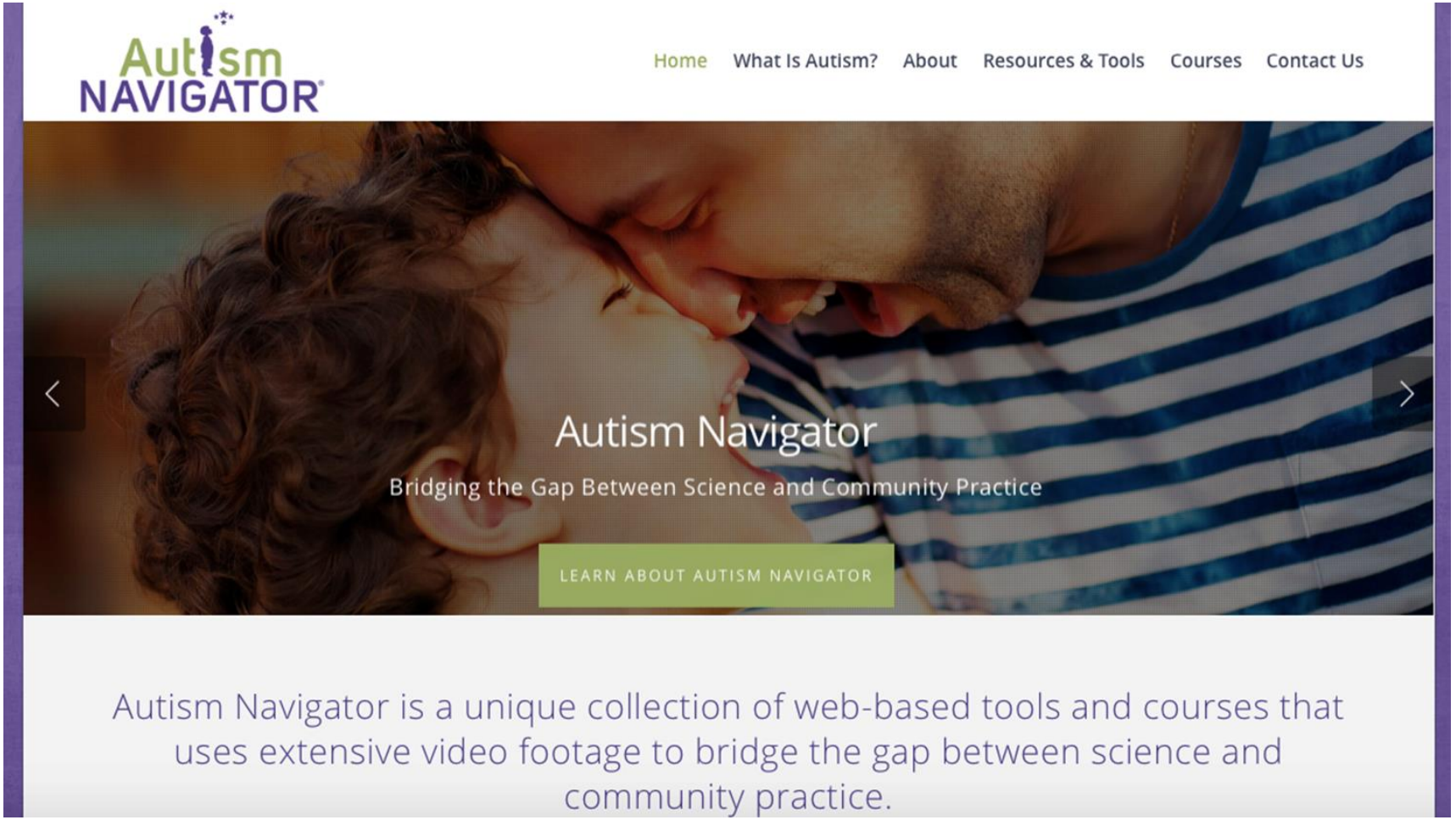
Collaborative Coaching

- Coaching is a method of transferring skills and expertise from a more experienced and knowledgeable practitioner to a less experienced one.
- Adult learning and collaboration
  - Dunst and Trivette (2012) meta-analysis study:
    - Active-learner participation
    - Multiple adult-learning strategies result in the greatest effect sizes.
    - Offer information, have multiple opportunities to practice and opportunities to evaluate and reflect on their use of strategies.

Collaborative Coaching

Goal: To support early intervention providers in furthering their development in the areas of autism and effective caregiver coaching in natural environments by utilizing evidence-based teaming strategies in a community-viable manner.

Autism Navigator: Bridging the Gap Between Science and Community Practice



www.autismnavigator.com

Autism Navigator

- Features of the Tool:
  - Highly interactive web platform
  - Based on the most current research on autism
  - Extensive video footage, illustrating effective evidence-based assessment and practice
  - Experiential Learning Format:
    - Introduction of topic
    - Video clip
    - Commentary on the video observation
  - Pre and Post Testing along with periodic information "checks" in each unit

Autism Navigator for EI Providers

- 30 hour Knowledge and Skills course for early intervention providers
- Designed to increase the capacity of EI providers to better serve young children with or at risk for autism spectrum disorder (ASD) and their families.
- Instructional content integrates current research with real world examples of children and families
- Five units
  1. Improving Early Detection
  2. Collaborating with Families
  3. Developmental Perspectives
  4. Evidence-based Intervention Strategies
  5. Addressing Challenging Behaviors

Collaborative Coaching

- Combination of in-person and mobile coaching
- Mobile coaching
  - Video review
  - Telecoaching

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Benefits of Collaborative Coaching

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Collaborative Coaching

Tele-coaching Device

- Wearable
- Live Coaching
- Cost Effective
- Errorless Learning
- Supports all providers

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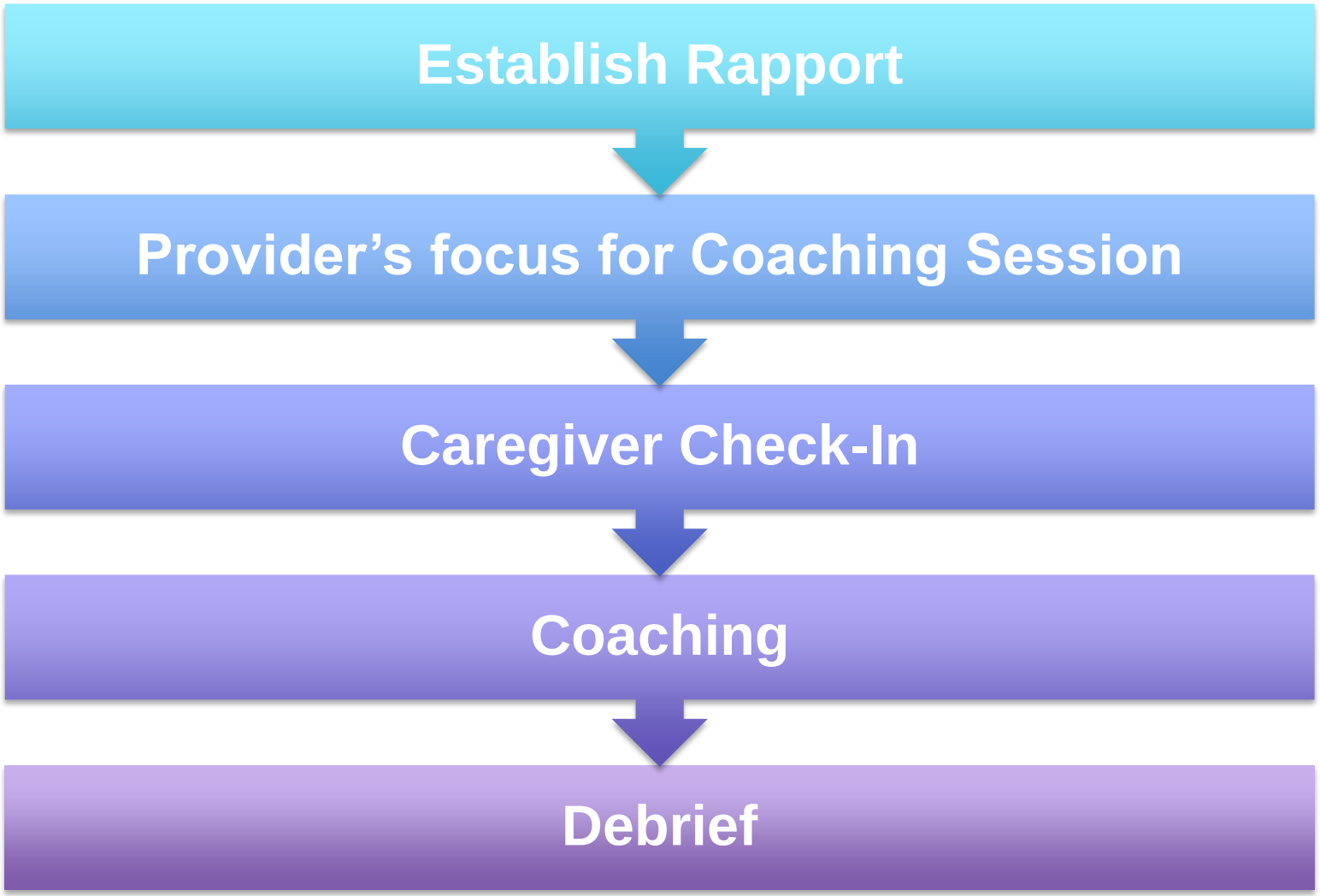
Georgia Tech

Video Review

Telecoaching



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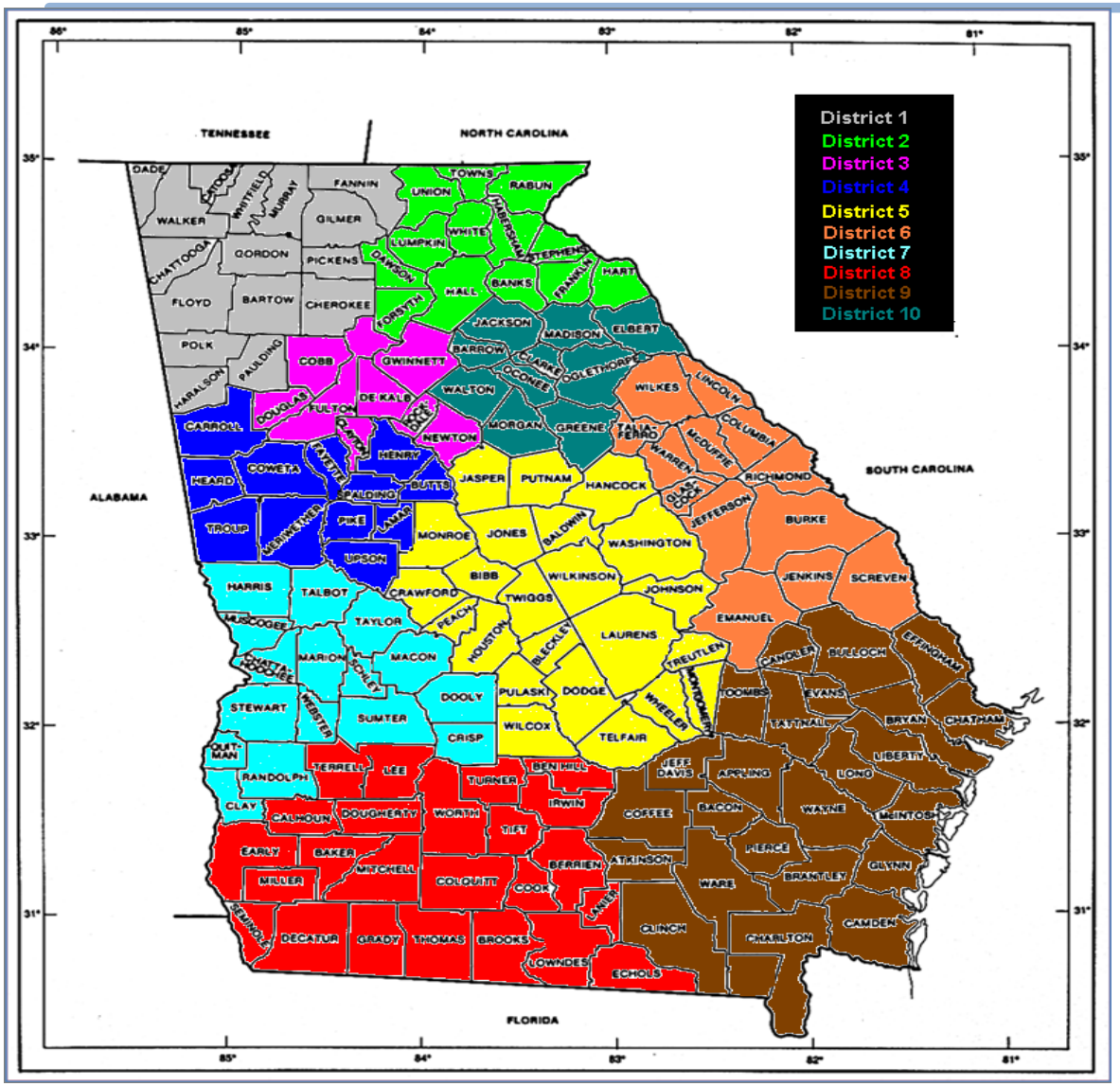
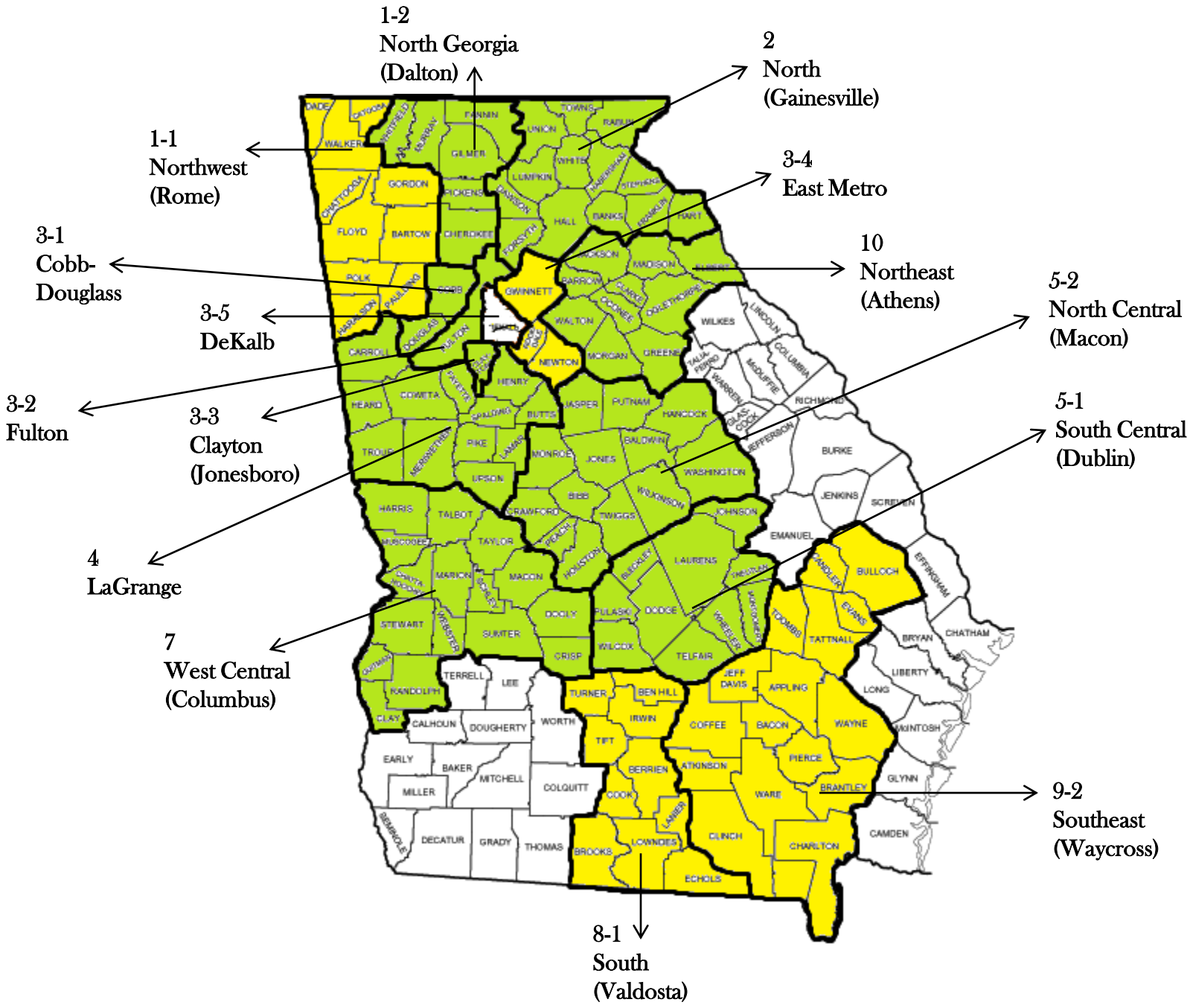
Coaching the Coach

Training in Early Screening, Detection, and Care for Infants and Toddlers Early Intervention/Babies Can't Wait



Early Intervention Because... Babies Can't Wait

Georgia Department of Public Health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North Georgia
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North
(Gainesville)
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Northwest
(Rome)
3-4
East Metro
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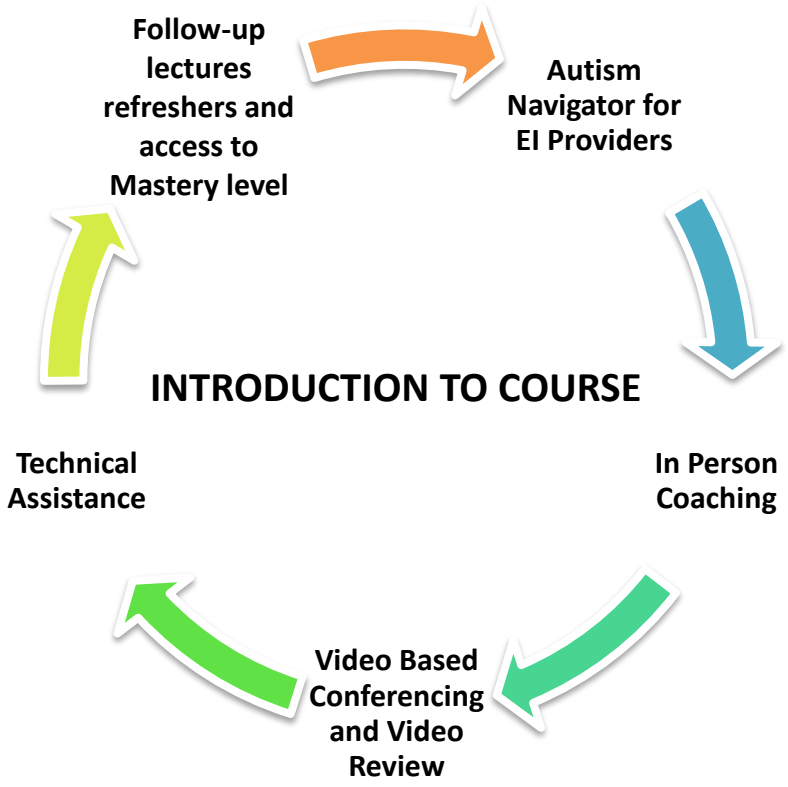
Cobb-
Douglass
10
Northeast
(Athens)
3-5
DeKalb
5-2
North Central
(Macon)
3-2
Fulton
3-3
Clayton
(Jonesboro)
5-1
South Central
(Dublin)
4
LaGrange
7
West Central
(Columbus)
9-2
Southeast
(Waycross)
8-1
South
(Valdosta)

Coaching Format

- Coaching will take place with each specialist/provider for 2 hours a week for 12 months
- Coaches will observe specialist providers with no less than 3 families
- Master coach will create an individual training plan for different families over time



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Autism Navigator™

Autism Navigator Development

Autism Navigator for Primary Care Physicians

BRIGHT from the START
Georgia Department of Early Care and Learning

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Kids Health First

Early Intervention Because... Babies Can't Wait

EARLY HEAD START

Autism Navigator for Early Head Start

Head Start

Autism Navigator for Head Start

Autism Navigator Partners

Autism Navigator for Early Intervention Providers

Ages 0-5: infants, toddlers, preschoolers

Science and Clinical Care → **Community Partners** → **Better Outcomes**

Vision: Maximize Potential for Children Today; Change the Nature of Autism for Children Tomorrow

- We are making major scientific advances to detect, diagnose, and intervene earlier.
- The developmental trajectories of children at risk for autism will change appreciably and change the future for these children and their families.
- Therefore, resources must be directed toward early intervention so we reduce the cost for a child with autism by 2/3 over their lifetime.

To make autism an issue of diversity, rather than disability.